


Truth, Deception, and Coercion; Communication Strategies Used by Caregivers of Children with Perinatally Acquired HIV During the Pre-Disclosure and Post-Disclosure Period in Rural Communities in South Africa

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Abstract

Typically, children with perinatal HIV (PHIV) receive antiretroviral treatment (ART) for a long time prior to receiving disclosure. Communication with children about HIV and treatment is critical for monitoring adherence and retention in care. However, there is a dearth of information on communication between caregivers and their children. This study examines what and how caregivers tell their their children about their illness and medication in the pre-disclosure and post-disclosure period. A qualitative study using semi-structured one-on-one interviews and focus group discussions was conducted with caregivers recruited via purposive sampling from a rural sub-district in South Africa. The interviews were analyzed using thematic analysis. The sample consisted of 38 caregivers, 24 of whom were the children's biological mothers, 20 had disclosed to the children and 18 had not done so. Caregivers who had disclosed had told their children the truth and named the disease as HIV, but communication about HIV was infrequent and focused on pill taking. Those who had not disclosed had lied, deflected illness-related information, and attributed the children's ill health to co-morbid conditions. To enforce adherence, most caregivers used coercion and threats of the grave consequences of non-adherence as a communication strategy. Those who had not disclosed used deception, deflecting, and coercion as strategies for coping through the pre-disclosure period. There is a need for healthcare workers to prepare, support, and empower caregivers to develop appropriate responses to children's questions and to understand the implications of deception on future full disclosure and children's acceptance of their HIV status.

Keywords

communication, caregiver, children, perinatal HIV, pre-disclosure, deception, deflection, South Africa, rural.

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Introduction

HIV disclosure is a significant event in children and adolescents with perinatally acquired HIV (PHIV), and the cornerstone of all HIV care. Knowing their own HIV status is an important milestone for children and adolescents with PHIV, leading to their attainment of independence in their self-care and to their taking their medications consistently.^{1,2} In spite of these benefits, many children and adolescents with PHIV remain uninformed of their HIV status, regardless of their receiving ART for extensive periods of time.^{3,4} In many settings in

sub-Saharan Africa (SSA), including South Africa, the rate of disclosure to children and adolescents with PHIV ranges from 13% to 60%.^{2,5,6} Moreover, existing data suggest that the HIV disclosure process often occurs late

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and in the adolescent period.⁷ A systematic review in middle- and low-income countries found median age of 13 years, with a range of 10 to 15 years.⁵

Delaying disclosure to older children and adolescents increases the risk of children defaulting or refusing to take their medication, and to poor self-care, which can lead to the development of drug-resistant strain behaviors. Delayed disclosure denies children the opportunity to make correct and informed decisions about their health and increases the risk of their transmitting HIV to potential sexual partners and others.⁸⁻¹¹ The benefits of timely and safe disclosure include improved adherence, retention in care, involvement of the adolescents in their care, and safer sex behaviors.^{2,7,12}

Although caregivers have been ascribed the role of disclosing to their children^{3,13} research shows that their communication with children about HIV is inadequate. This is despite the fact that children on lifelong ART start asking questions about their illness and taking regular medication.¹⁴ Several studies have reported a tendency of caregivers to give children untrue information about why they have to take their medicines. They substitute HIV with acceptable and less stigmatizing medical conditions in response to questions.^{13,15-17} The practice of deceptive disclosure (the use of a non-HIV-related reason for explaining the illness and healthcare visits) is common in many settings in SSA.^{2,5} Caregivers lie in order to protect their children from the negative emotional impact of disclosure, and to deflect attention from HIV.¹³

In contrast, when full disclosure occurs the caregivers tell the children the name of the illness they suffer from, provide disease-specific information, and tell the children how they acquired the disease.^{15,17,18} This is different from partial disclosure, in which the children are given some but not all of the information about their illness. They may be informed of the need to take medicine in order to keep their illness at bay without naming the illness as HIV.¹⁹ Research suggests that often disease-specific information in full disclosure is limited to naming the disease, explaining that there is no cure, and saying that they will have to take the medication all their lives. The disease-specific information is based on the caregivers' limited HIV-related knowledge.²⁰

While there have been many studies describing the barriers against and benefits of disclosure to children,^{8,21-23} there has been inadequate research on what caregivers tell their children about their disease and medication. It should be noted that since the caregivers are tasked with disclosure to their children, divulging information on what the medication they take is for, and how to take it correctly is primarily the responsibility of the caregivers. Furthermore, available disclosure guidelines for

children and adolescents with PHIV do not state what messages should be communicated to children during the disclosure.²⁰ What compounds the problem is the lack of or limited interventions that support caregivers in the disclosure process. As a result, many caregivers lack disclosure skills and feel unprepared to undertake disclosure to children.^{13,24}

It is important to examine the messages that children with PHIV receive, particularly because in many settings, disclosure often involves the caregiver only.^{3,17} Communicating with older children and adolescents about their HIV diagnosis and treatment is crucial to enable them to actively participate in self-care and adhere to ART.^{14,25} A significant public health challenge is that the disclosure rates in South Africa and other parts of SSA are low^{2,5,6} and children receive ART for a long time prior to disclosure. However, there is a dearth of data on what children are told about their pill taking and regular clinic attendance in the pre-disclosure period. The few studies reporting on the practice of the deflection of HIV-related information were not designed specifically to investigate communication between the caregiver and their children. The purpose of this study is to examine what and how caregivers who had disclosed and who had not disclosed had told their children about their illness and medication in the pre-disclosure and post-disclosure periods. It is important that caregivers maintain open communication with their children to ensure their adherence to lifelong ART and the adoption of self-care.²⁶

Methods

Study Design and Setting

This qualitative study combined in-depth interviews (IDIs) and focus group discussions (FGDs) to collect data from caregivers of children with PHIV. The setting of the study was a rural sub-district in the North West Province, South Africa. The sub-district is situated far north of Pretoria, approximately 102 km. There are 22 primary health care (PHC) facilities comprising 24-hour community health centres and 8-hour clinics in the sub-district. The facilities provide a comprehensive primary health care package, including HIV counselling and testing, adherence counselling, ART initiation, and the issuing of ART to adults and children. At the time of the study, about 480 children aged between 6 and 15 years were in HIV care and active on ART in the health district. The facilities have been providing ART to children since 2010 through the Nurse Initiating Management of Antiretroviral Treatment (NIMART) programme, in which nurses initiate HIV patients on ART.²⁷ In this

district, the first cohorts of children with PHIV were referred from a district hospital as part of the down referral of children to access ART in clinics under the NIMART programme.

Recruitment and Data Collection

The research population consisted of caregivers who accompany children with PHIV to health facilities for routine HIV care and ART refill. Caregivers were selected via purposive sampling from four randomly selected health facilities. The recruitment of caregivers who had disclosed and those who have not done so was done by the lead investigator with assistance from the clinic staff. Prior to data collection, the lead investigator made arrangements with the facility managers to provide an overview of purpose of study and plans for data collection. Purposeful sampling involved the selection of caregivers who could inform the phenomenon under investigation.²⁸ Caregivers of children aged 6 to 15 years on long life ART and receive HIV care in the selected facilities were eligible to participate in the study.

The caregivers who met the criteria for inclusion in the study were approached in the mornings during the consultation of their children. Those who volunteered to participate in the study were offered either a one-on-one interview or the opportunity to participate in a focus group session, if the numbers allowed the researchers to form focus groups of 5 to 10 participants per group as recommended by Krueger and Casey.²⁹ The researchers found that even though the number of children with PHIV who were enrolled in HIV care in the sub-district was large, a proportion of the adolescents were unaccompanied to the clinics by caregivers. This affected the formation of focus groups. We defined a caregiver as a biological parent, grandparent, foster parent, or other adult family relative who is responsible for the day-to-day care of the child.

We conducted 4 FGDs and 16 IDIs with 38 caregivers between July and September 2018. The lead investigator (MM) and a research assistant (the researchers) trained in the conduct of IDIs and FGDs collected data through semi-structured interview guide containing open-ended questions to solicit responses during the interviews. The investigators (MM and SM) had designed the interview guide (the same guide was used for the IDIs and FGDs), which was later translated into Setswana, the local language spoken in the sub-district. The development of the guide had been informed by previous qualitative research on disclosure conducted in South Africa and elsewhere.^{14,20} The guide asked questions pertaining to caregiver practices of disclosure,

their opinions about disclosing to children, what motivates them to disclose, what they tell their children about their illness and medication, how they communicate with their children, and the strategies they use to conceal the HIV diagnosis from their children. In addition, the researchers asked follow-up questions and probed to clarify or verify responses. Data collection ceased once the interviews were no longer generating any new themes.³⁰ The second author (SM) supervised the data collection and trained the lead investigator and research assistant on qualitative data collection.

Interviews were conducted in a private interview room at the health facilities. We conducted the interviews after the caregivers and their children had completed the routine medical check-up or ART refill. Interviews were conducted in the Setswana language to allow the caregivers to express themselves in detail and were audio recorded with the permission of the participants. We obtained signed informed consent from all participants prior to the data collection, informed them about the voluntary nature of the study, and assured them of the confidentiality and anonymity of the process. Each focus group discussion lasted about 60 minutes and each group consisted of about 5 participants, while the IDIs lasted about 45 minutes.

At the end of each interview, the caregivers completed a short tool to collect information about the child and caregiver demographics. The tool also captured the child's clinical data, including the duration of ART, the disclosure status, the schooling status, and the relation with the caregiver.

Data Analysis

Data analysis was done in accordance with Braun and Clark,³¹ following a thematic analysis methodology using a combined deductive and inductive approach. The inductive approach determined the meanings that emerged from the data, while the deductive approach looked for categories and meanings in the data that were determined a priori, based on the interview guide. The verbatim transcription of the audio files, the translation, and the reading of the transcripts were the initial processes of the data analysis. This was performed by the lead investigator and the research assistant, both of whom are fluent in the local language. The interviews were conducted in the local language (Setswana) and translated into English. After the translation, the authors separately read selected transcripts several times to familiarize themselves with the data. Through the process of the repeated reading of the transcripts, the authors identified emerging codes and developed a list of codes. They then met several times to reconcile the

emerging codes and develop a codebook. Once they had consensus on the definition of themes, the codebook was completed. The transcripts were then entered into NVivo version 12³² and the coding was applied to all the transcripts. Analysis continued until rich themes and sub-themes that reflected the responses of the caregivers were arrived at.

Credibility, dependability, transferability, and conformability are strategies used to attain rigor in qualitative research.³³ To attain rigor in this study we conducted the interviews in the local language, transcribed the interviews verbatim, used a good audio recorder, and analyzed the data using NVivo qualitative software. In addition, we conducted in-depth and focus group interviews, held peer-debriefing sessions throughout the data collection, and kept an audit trail. Lastly, the analysis of the data was done by both authors to reduce potential investigator bias.³⁴

Ethical Consideration

The study was approved by the Ethics Committee of Sefako Makgatho Health Sciences University Research and Ethics Committee (SMUREC/H/254/2017:PG). Permission was obtained from the North West Department of the Health Research Committee and the relevant authorities. Written informed consent was obtained from each participant, and anonymity and confidentiality were ensured by not capturing the participants' personal identifiers and those of their children. Instead, pseudonyms were used during the interviews.

Results

Characteristics of the Participants

The sample consisted of 38 caregivers of children and adolescents with PHIV aged between 25 and 84 years. All of the participants were females. Most (24 out of 38) were the children's biological mothers, 27 reported their HIV status as positive, 20 had disclosed to their children, and 18 had not done so. The children were aged between 6 and 15 years, and most (22 out of 38) were in the age category of 11 to 15 years. Their mean age was 10.8 years, their mean age of disclosure was 9.3 years, and 20 of the 38 were males. The mean intended age of disclosure for the caregivers who had not disclosed was 12.4 years (Table 1).

Themes

Four main themes emerged from the analysis of the in-depth interviews and the focus group discussions,

Table 1. Demographic Profile of Caregivers and Children.

Variable	Number	%
Gender		
Female	38	100
Caregiver age		
25-44 years	25	66
45-64 years	11	29
65-84 years	2	5
Marital status		
Single	27	71
Married	11	29
Disclosed child status		
Yes	20	53
No	18	47
Relationship to child		
Biological mother	24	63
Grandmother	8	21
Aunt	5	13
Foster parent	1	3
Caregiver level of education		
Primary level	5	13
Secondary level	21	55
Completed grade 12	12	32
Caregiver HIV status		
Negative	10	26
Positive	27	71
Unknown	1	3
Child age		
6-10 years	16	42
11-15 years	22	58
Child gender		
Male	20	53
Female	18	47
Child level of education		
Primary	33	87
Secondary	5	13

namely telling the truth, coercion and threats, avoiding talking about HIV, and deception. Under the theme telling the truth, 6 sub-themes emerged (Table 2).

Telling the Truth

Most caregivers felt that it was important to tell children that they have HIV. Their narratives revealed that during the conversation or disclosure event, they told the children the name of the disease, explained the source of the child's infection, explained the routine visits to the clinic, taught the child about the need to adhere to ART, and taught the child about protecting others from HIV transmission.

Table 2. Themes and Sub-Themes of Benefits.

Themes	Sub-themes
Telling the truth	Revealing the HIV status Explaining the source of the child's infection Explaining the routine visits to the clinic Telling the child about the implications of adherence to ART Teaching the child about protecting others from HIV transmission
Coercion and threats	
Avoiding talking about HIV	
Deception	

Revealing the HIV Status

"I told her that she is taking treatment because she is HIV-positive and that the medication is for lifetime and she has to take on a daily basis." (Mother of a 13-year-old girl.)

"I had to tell her that she is HIV-positive, but I explained that it doesn't mean that she has AIDS because there's a difference between HIV and AIDS. I told her that she has to take the medication and that is for a lifetime." (Mother of a 14-year-old girl.)

"I explained to him that the reason he has to take medication all the time is because he is HIV-positive. I told him that he was infected with the disease when I was pregnant with him." (Mother of an 11-year-old boy.)

Explaining the Routine Visits to the Clinic

The disclosure conversation between caregivers and their children is often triggered by the children's repeated questions regarding the uptake of medication and the routine visits to the clinic. When the topic arose, it prompted caregivers to disclose. They explained why they had to take the children to the clinic every month in relation to taking ARV medications.

"The child was asking me why he has to regularly attend clinic visits and I had to inform him that he is taking treatment for untreatable illness because he is infected with HIV." (Aunt of a 14-year-old boy.)

"I told her that the reason she regularly attended clinic was because she is taking treatment for an incurable illness because she is infected with HIV." (Mother of a 6-year-old girl.)

"I said to her 'We [mother and child] are taking pills for HIV and that we are going to take them for the rest of our lives every day at the same time to suppress the disease and live normal like any person.'" (Mother of a 12-year-old girl.)

Explaining the Source of the Child's Infection

The narratives of caregivers revealed that they felt that it was important to tell the child how they had been infected with HIV. In their communication with their children, the caregivers who were not the biological mothers of the child often blamed the diseased mother for the infection.

"I explained that it is not his own doing but he got it [HIV] from his mother. I told him that if his mother had attended the clinic when she was pregnant with him, he wouldn't have been infected." (Grandmother of a 13-year-old boy.)

"We explained to her that she has HIV and she got it from her mother. That is why she is also HIV-positive today." (Aunt of a 12-year-old girl.)

In contrast, to explain the source of infection biological mothers told their children that they had been infected during pregnancy because there was no medication to prevent the mother-to-child transmission of HIV.

"I explained that he got it [HIV] when I was pregnant with him. I explained that I was already HIV-positive when I was pregnant with him; that is how he was infected. I explained that I did not take medication that would prevent transmission of HIV from mother to child because I did not test during my pregnancy." (Mother of a 14-year-old boy.)

Transmitting HIV to Others

The caregivers were mindful that their adolescent children might become sexually active and emphasized the importance of informing them of their HIV status before they reached puberty. Their discussions with their children stressed that they could transmit HIV to others during play with other children or through sexual activity in older children. As such, they taught their children to protect others from infection

"I told her that as she plays with other children it might happen that she gets hurt and bleeds. I told her that she must at all costs avoid a situation where her blood come into contact with other children. I told her that she must come back home, wash the wound, and close it off. I also told her that she must not try to help wash someone's blood." (Mother of a 10-year-old girl.)

"I told her to stay away from unprotected sex when she grows up. If she wants to have sex she must make sure that she uses condoms." (Grandmother of a 14-year-old girl.)

"I explained to him and his aunt told him that he is old now and if he is having sex with girls he must use condoms." (Grandmother of a 15-year-old boy.)

Teaching Children about the Implications of Adherence to ART

Some of the caregivers were prompted to inform their children about their HIV status because they had asked what the medicines were for and when they could stop taking them. In their discussion, the caregivers explained to their children about HIV infection and its relationship to their medication.

"She asks questions about what the tablets are doing to her body and how they are going to help her. I then explained how the tablets help her and what they do to her body. I also explained that she would drink them for the rest of her life." (Mother of a 12-year-old girl.)

"She asked me how her body would look if she doesn't take her treatment. She also asked if she was going to be sick if she did not take her medication. I told her that she would lose weight, get sick if she does not take her medication." (Mother of an 8-year-old girl.)

"I explained to her in detail what HIV is and even mentioned the importance of treatment that will assist to suppress her virus." (Foster mother of an 11-year-old girl.)

As already stated, poor adherence was the most common reason caregivers disclosed their HIV status to their children. As such, most caregivers expected that disclosure would promote adherence to the regime of medication. Thus, supporting the child's adherence was very important for them.

"I explained to him that I am the one who will always go to the clinic to collect his treatment. I also told him that I am always be there to remind him to take his medication; and I will make sure that he has food to eat before taking his medication." (Grandmother of a 12-year-old boy.)

"I told him to continue taking his medication and taking good care of himself." (Grandmother of a 12-year-old boy.)

"The message I gave my child was that HIV is incurable. I also told him that HIV lives in a person's blood and in order to control it, one has to take medication." (Mother of a 14-year-old boy.)

In most cases, their encouragement to adhere was often focused on reminders to take medication at the required times.

"I tell her whenever I go and collect her medication for her and I also remind her that she will continue to take the medication at the same time daily." (Mother of a 10-year-old girl.)

"I set a reminder on my phone in order to remind her to take treatment." (Foster mother of an 11-year-old girl.)

"I just say. . . boy it's time to take your pills. Please take them for the sake of your life because they will enable you to live longer." (Mother of an 11-year-old boy.)

Coercion and Threats

Children normally receive ART for a long time before they receive disclosure. When they do not have information about why they have to take medication, poor adherence sets in. In some cases, caregivers used coercion to force their children to adhere to treatment. The coercion by caretakers was underpinned by threats of the consequences of refusing to take treatment, including hospitalization or death, and was common among both caregivers who had disclosed and those who had concealed the HIV status of the child.

"She wanted to refuse to take his medication and then I have to force her." (Anon-disclosed aunt of an 11-year-old girl.)

"I scold him or take a stick and put it in front of him and demand that he drinks the medication, of which is wrong but what can I do." (Disclosed mother of a 14-year-old boy.)

"I told her that if she doesn't take her medication she will die." (Disclosed mother of an 8-year-old girl.)

"She used to stress me and I told her that if she does not take her medication, she will land in hospital." (A non-disclosed aunt of a 14-year-old girl.)

Avoiding Talking About HIV

Even though most of the caregiver believed that children should be told about their HIV status, those who had not done so wished to avoid telling their children about HIV for as long as possible. The biological mothers rarely engaged openly in conversations about HIV and how the transmission to the child occurred. For some, when discussions around HIV did occur they were without explanations, and the caregivers avoided follow-up questions to avoid addressing the question of transmission.

"I told her that we are both HIV-positive. I explained that it is not important to know how we got infected but as they told us at the clinic we need to accept that we are HIV-positive." (Mother of a 10-year-old girl.)

"She asked me how she got infected by HIV and I said I don't know. I only know that it is transmitted through blood or breastfeeding. I told her that I tested HIV-positive and also wondering how I got it." (Mother of a 13-year-old girl.)

"I told her that she has HIV. I told her that I don't know how HIV started or where it's coming from. I just grew up and discovered that it exists." (Mother of an 8-year-old girl.)

"We don't really talk too much about HIV ever since I told her about her status." (Aunt of a 12-year-old girl.)

Deception

To avoid the disclosure to their children, caregivers provided non HIV-related explanations as reasons for their having to take medicine daily and make repeated visits to clinics. They told their children that they were taking the medicines for the co-existing medical conditions. They replaced the HIV with conditions such as asthma as explanations in response to the children's persistent questioning

"I told him that he is taking high blood pressure treatment and I am also taking it. He was asking me questions and high blood pressure was the only option I was left with because he was curious by then." (Granny of a 13-year-old boy.)

"He ask me about the medication and I tell him it is for chest pain. He complains about having to take them every day." (Mother of a 6-year-old boy.)

"I tell him it's for TB. He was once on TB treatment for 9 months. He knows he will take his treatment for his whole life but knows that the treatment is for TB." (Mother of an 8-year-old boy.)

Caregivers who had not disclosed often lied to their children when the children asked why they needed to take regular medication. The caregivers avoided the issue by lying or not revealing the full truth about the illness. For example, they would not name the disease but would tell their children that they are taking life-long treatment. They also provided deflected illness-related information to conceal the truth about their children's HIV status rather than provide answers to the children's questions. The narratives with the caregivers revealed that they expected to continue telling such lies until the occurrence of disclosure.

"When my child started taking treatment, he asked me what the treatment was for. I told him that it was for fever. I explained that the treatment is meant to cure the fever. However, when the flu was cured, I told him that the treatment worked well so he should continue taking it." (Mother of a 12-year-old boy.)

"Every time when we come for clinic visits I just tell him that you are here to take your lifelong medication even though I have not yet explained the condition he is taking the treatment for." (Mother of an 11-year-old boy.)

Discussion

The study included caregivers who reported that they had informed their children about their HIV diagnosis and those who had not. It revealed that only slightly over half (20 out of 38) of the caregivers had disclosed to their children, even though both those who had disclosed and those who had not believed that children should know their HIV status. The caregivers who had disclosed had told their children the truth about the disease. They had named the disease and told the children that they have HIV. The findings suggest that full disclosure occurred to all the children who were told that they had HIV.¹⁹ The children's persistent questions about why they needed to take regular medication and make regular visits to the clinic triggered disclosure. Consequently, the discussion with the children was limited to naming the disease, explaining that HIV is incurable, that they will take medication all their life, and the reasons for their regular clinic visits. When disclosure was triggered by a refusal to take the medication, the naming of the illness was followed by a discussion about how ART works and the importance of adherence. Prior studies have reported similar findings.^{13,20,25}

Eighteen caregivers had not informed their children that they had HIV. We found that, consistent with previous studies,^{9,18,35,36} such caregivers lied to their children about the reasons for taking their medicines and going to the clinic. They used deception when children

questioned them about their status and why they were taking the medication, although this presented them with opportunities to tell their children that they had HIV. To continue avoiding disclosure, the caregivers deflected the illness-related information rather than provide answers to their children's questions. They told their children about co-morbid conditions and attributed their ill health and clinic visits to less-stigmatized conditions such as asthma, tuberculosis, fever, rashes, or other chest problems. The practice of deflected disclosure (the use of a non HIV-related reason for explaining the illness and healthcare visits) to children and adolescents has been reported in several previous studies.^{9,18,37-39} There is a need for HCWs to assist caregivers by telling them how to communicate truthfully and by empowering them to understand the implications of their deception on the future full disclosure and the children's acceptance of their HIV status post disclosure.³⁷

Deflected disclosure is a strategy of deceptive disclosure that caregivers often use, rather than providing answers to their children's questions, frequently out of concern for the children's psychological well-being.⁵ However, in this study as in others, caregivers used avoidance and deception when they felt less prepared to disclose and lacked the self-efficacy to deliver the disclosure messages and answer questions about the source of the HIV infection. Moreover, the caregivers intentionally provided misleading information to draw their children away from considering HIV as a possible diagnosis.^{10,36-38} The practice of deflection and deceptions has negative outcomes for children and adolescents, mainly in relation to adherence and engaging in safe sexual practices.⁵ Deflected disclosure increases the difficulties for caregivers to eventually disclose.¹³ Researchers have found that children who were told lies before disclosure perceived deflection as deception and a betrayal of trust, experienced resentment, disappointment and anger towards their caregivers for having kept silent and having lied about their diagnosis.^{1,15,40-42}

In South Africa and in other SSA countries children receive ART for a long time prior to disclosure, given the reported low disclosure rates. While continued communication about HIV medication is critical for monitoring adherence to HIV medication,¹⁵ we found in the current study that caregivers' communication with children about ART was infrequent and focused on pill taking. Similar patterns of communication were reported in studies conducted with children who described communication with their caregivers as being limited to their taking their medicine.^{35,43} Similarly, in the current study most of the conversations between caregivers and children revolved around medicines rather than the HIV

diagnosis, particularly among caregivers who had not disclosed. The findings of this study are consistent with those of other studies^{35,37,43} and underscore the importance of on-going communication about ART between caregivers and children to create open spaces for communication and thus to foster adherence.

The current study has established that when children threatened to stop taking medicine, or refused to take their ARVs, caregivers used coercion and threats of the grave consequences of non-adherence as a strategy to enforce adherence. Other researchers have reported similar strategies used to force children to take ART doses at the required time.^{13,20,37,43} We found that whilst coercion was a strategy that was used by all caregivers, the practice was common in the absence of disclosure, as these caregivers could not mention HIV in discussions with their children. The punitive strategies used by caregivers to enforce adherence may undermine the children's pill taking and should be replaced by interventions that help them to incorporate routine pill taking in their daily lives.⁴³

Prior studies have reported that caregivers stress the importance of telling their children about the source of infection so that the child learns about other modes of HIV transmission besides knowing HIV to be sexually transmitted.¹³ Other researchers have noted that caregivers explain the child's source of infection to make the child understand the nature of the disease.^{16,25} Similarly, caregivers in the current study discussed the source of the child's infection, particularly for children who wanted to know how they were infected. We found that non-biological caregivers explained the source of infection with ease, and in so doing, they blamed the deceased biological mother for the infection. Research suggests that the blaming of the diseased mother is unintentional, but caregivers use it as a strategy to alleviate the children's pain when learning about their HIV status.¹³

In contrast, biological mothers seldom engage in conversations about how transmission had occurred, even when asked about the source of the infection. Most biological mothers desired to avoid dealing with the question of transmission because they realized that discussing the child's source of infection would mean the inevitable disclosure of their own HIV status. Some studies have highlighted mothers' dilemma about open discussion with their children on matters related to sexuality. Mothers worry about the shame of being seen as the source of the infection and subsequently being blamed by the children.^{10,16,36,44,45} This explains why mothers lie or use deflective disclosure in their discussion about the source of their children's infection. There is a need for HCWs to prepare and support caregivers to develop

appropriate responses to children's questions about the source of infection instead of deflecting the questions.^{35,46} This is particularly important because HIV is often presented as a sexually transmitted disease and perceived as a fatal disease.⁴⁷

Our study agrees with the current literature^{14,38} that open, ongoing communication with children about HIV following disclosure is infrequent and focusses on taking tablets. Caregivers were silent about HIV and most avoided open discussions in their households in the pre- and post-disclosure period. Bernays et al⁴⁸ argue that disclosure is often turned into a medical issue only, and is otherwise silent. Similarly, previous studies conducted in South Africa and elsewhere have found that even when full disclosure has taken place, disease-specific information to children is limited and is based on the caregivers' limited HIV-related knowledge.^{14,20} Ascribing the responsibility of disclosure to the caregiver alone has implications for what children are told, in view of the evidence of caregivers' lack of knowledge and of the skill of disclosing to children.^{17,24}

The caregivers who had disclosed emphasized to the child the potential of transmitting HIV to others. This was done to teach the children how to protect their playmates from accidental exposure to HIV, and how to protect their potential sexual partners from HIV infection.^{13,14} The researchers noted that often this emphasis is used as a means to control the child's sexual behavior.¹³ In the current study, the caregivers were found to have instructed the children not to have sex and or to use protection if they engaged in sexual activities.

We found that when disclosure was triggered by adherence challenges and persistent questioning of the caregiver by their children, the result was disclosure without adequate preparation. This suggests that children receive full disclosure during a single disclosure conversation, which deprives them of adequate information to gradually learn about their HIV status and to manage their disease. The findings of the current study underscore the need for interventions to equip caregivers with adequate HIV-related knowledge, information, and skills to prepare them to engage in open discussion with their children during disclosure and post disclosure.

Limitation of the Study

The results of this study are based on a small sample of caregivers from a small, rural sub-district, do not represent the views of all caregivers in all settings, and cannot be generalized. However, the study examined an important practice in the HIV disclosure continuum for children with PHIV, and the findings provide critical data on

the practice of disclosure to inform interventions for open communication between caregivers and children.

Conclusions

We found that caregivers missed opportunities for truthful, open discussions with children about their illness and why they were taking medicines. Our findings revealed that most caregivers who had not disclosed used deception, deflection, coercion and threats as coping strategies through the pre-disclosure period. The frequent use of punitive strategies by caregivers to enforce adherence should be replaced by interventions that help children to incorporate routine pill taking into their daily lives.

Health care providers should equip caregivers with the knowledge and skills to develop appropriate responses to children's questions and avoid deception and deflecting questions about HIV during the pre-disclosure period. In addition, guidelines for HIV disclosure need to be cognizant of deflected disclosure as a strategy and provide alternative strategies for managing the pre-disclosure period

This study corroborates prior studies that have found that relying on caregivers alone to communicate messages on diagnosis and treatment to children with HIV may be inadequate. Therefore, the involvement of HCWs in the disclosure process to prepare and support caregivers for disclosure is an important step in ensuring that children receive age-appropriate information about their disease and prepare them for self-care.

Author Contributions

MM and SM conceptualized the study; MM collected data; MM and SM analyzed and interpreted data; MM drafted the manuscript; SM critically revised the manuscript; MM and SM gave final approval of the manuscript.

Declaration of Conflicting Interests

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Ethical Consideration

The study was approved by the Ethics Committee of Sefako Makgatho Health Sciences University Research and Ethics Committee (SMUREC/H/254/2017:PG). Permission was obtained from the North West Department of the Health Research Committee and the relevant authorities. Written informed consent was obtained from each participant, and

anonymity and confidentiality were ensured by not capturing the participants' personal identifiers and those of their children. Instead, pseudonyms were used during the interviews.

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Availability of data and resources

All data used in the study are available from the lead author on request

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